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Patient choice modules for summaries of clinical effectiveness: a proposal

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Evidence based health care has become the accepted basis of good clinical practice, and many efforts are being made to implement it. Evidence based patient choice, defined as offering patients research based information and the opportunity to influence decisions about their treatment and care, has yet to achieve the same status. We believe, however, that it is fundamental to high quality patient care.

In our ideal world difficult or controversial healthcare decisions would routinely involve health professionals deliberating with patients about the harms and benefits of all available options, as well as patients' treatment goals and risk tolerance. For key medical decisions, patients and doctors would expect to work through the evidence and decide on a course of action together. Patients who wished to delegate decision making to a doctor or surrogate decision maker would still be given the information that they wanted.

Various strategies may be needed to achieve this widespread implementation of evidence based patient choice.[1 2] In this article we focus on a strategy to improve the accessibility of information resources to support evidence based patient choice. The books, journals, and websites that currently provide evidence based information about the effectiveness of healthcare interventions could provide the infrastructure to support patients' participation in evidence based decision making. These information sources should incorporate consumer focused summaries of relevant research evidence and links or pointers to well designed and tested decision aids for patients. These summaries should be made available to patients before, during, and after consultations. Doctors and health systems could use and distribute them as an adjunct to clinical care. They would also be available to the public generally. The news and information media, patient groups, and others would draw on patient choice summaries to present the benefits and limitations of medical screening and treatment.

We suggest that a patient choice module could be added to systematic reviews and other key assessments of health technology. Such a module would take various forms but would be designed to facilitate patient involvement in decision making. Such modules would be key data sources for developers of products like decision aids, leaflets, and interactive websites for use by patients. They would also be helpful in reorienting thinking across the healthcare system about patient choice informed by evidence. International collaboration should help the development of appropriate information to support patient involvement in treatment decision making.

Summary points

Evidence based health care should be accompanied by evidence based patient choice, defined as offering patients information about treatment alternatives, the benefits and harms of each, and offering patients a key role in decision making

Evidence based patient choice will increase demand for patient oriented information about medical effectiveness.

Time constraints in modern consultations necessitate that such information be widely available before, during, and after the consultation

Patient choice modules that follow a standard template could be added to systematic reviews and other key assessments of health technology

Need for information

A high degree of patient involvement in clinical decision making creates a demand for information.[3 4] This demand will be met only if the required data are easily available. Summaries of research evidence about the effects of healthcare interventions are now becoming accessible to clinicians from sources like *Clinical Evidence*[5] and the *Cochrane Library*,[6] but these sources are not designed for patients and are largely inaccessible to them. Brief consumer synopses are now being added to Cochrane Collaboration reviews, but these may not provide enough detail for people facing decisions about their care. More systematic efforts are needed to develop patient oriented summaries.

Research in ethics,[7] the doctor-patient relationship,[4] decision analysis,[8] shared decision making,[9] and evidence based medicine converge to suggest a

Table 1 Patient decision template for treatment options

Required element	Key patient questions	Information provided
Clinical condition reported	What are the characteristics of my diagnosis/disease/disorder?	Details of clinically important subgroups
Patient decision situation	What are the different ways this disorder can be treated?	Options for surgical treatments, medical treatments, watchful waiting, complementary therapies
For each treatment option:		
Treatment processes	What kind of treatment is it? How much time does it involve? What do I have to do to undergo this treatment?	Mode and duration of treatment, nature of patient involvement
Outcomes and probabilities	What are the chances of improvement over the next *x* days/weeks/months/years or over my lifetime?	Rates for different outcomes over various times, absolute number improved, improvement rate
	What kinds of side/toxic effects can happen, and what are the chances of each?	Rates for different side effects
Value tradeoffs	What are the tradeoffs between length of life and quality of life?	Material for clarification of values
	If length of life is not affected, what are the tradeoffs among the inconveniences, costs, chances of side effects, etc, in order to gain a benefit like symptom relief?	
	Where can I get descriptions of other patients' experiences?	

redesign of patient oriented information. Traditionally, such information makes a recommendation about an intervention from an authority and then explains how it works and why it is good for the patient. In contrast, information to support evidence based patient choice offers a description of the various possible interventions (including no intervention), a comparison of their consequences (benefits and harms), and an opportunity to consider these consequences in relation to life circumstances and patient preferences. Research on the efficacy of formal decision aids based on this approach has shown that they can help patients in several ways.[10] Patients develop an understanding of what is involved in a particular treatment choice, are clearer about what is important to them, and can communicate their preferences to their doctors. As a result, they gain knowledge, show high satisfaction with their decisions and with the decision making process, and have less decisional conflict. There is also some evidence that these aids can modify inordinately high or low use of healthcare resources.[11]

The design template for patient oriented evidence

We suggest a basic template for patient decision modules that is based on theoretical, methodological, and evaluative work. A common minimal set of elements has been found in the diverse tools that have been produced to support shared decision making.[10 12 13] The key elements of these formal decision aids are a description of the disease or condition, an outline of what options are available, and the probabilities of the beneficial and harmful consequences that follow from each option for subgroups of the population. Additional optional elements include a description of different patients' experiences with the medical intervention and its side effects, a rating of the importance of each outcome that could occur (positive and negative), guidance on making a follow up plan, and explicit strategies for communicating with healthcare professionals and partners or families. The data that can be supplied by systematic reviews are the available options, the probabilities, and sometimes outcome descriptions reported as narratives or in terms of patient values (utilities). Table 1 shows how a patient decision module could be organised for treatment options.

Screening poses an additional information burden because the sensitivity and specificity of the test and the false positive and false negative rates in tested populations need to be included. Table 2 shows how the patient decision module could be organised for screening options. There is also a strong theoretical

Table 2 Patient decision template for screening options

Required element	Key patient questions	Information provided
Clinical condition to be prevented	What are the characteristics of this diagnosis/disease/disorder?	Expected incidence of disease in 1, 5, 10, and 20 years among untreated patients
		Identification of clinically important subgroups at risk
		Probabilities of key patient oriented outcomes (harms and benefits) caused by the disease if untreated
Patient decision situation	What are the different ways this disease/disorder can be detected/prevented?	Options in terms of screening, watchful waiting, medical preventive strategies, lifestyle preventive strategies
Effectiveness of treatment if detected by screening	If the disease/disorder is detected by screening how effective is the subsequent treatment?	Probabilities of key patient oriented harms and benefits, in terms of difference from rates in unscreened population
		Absolute risk reduction
		Relative risk reduction
Screening options (for each possible test)	What are the side effects of taking this test?	Rates of side effects
	How accurate is this test?	Rates for false positive and negative results
	What happens after I take the test?	Follow up procedures
Value tradeoffs	Am I willing to go through the potential anxiety of screening and treatment now to prevent a disease in the future?	Material for clarification of values
	What impact will screening have on my family and professional life?	

and empirical basis for using the same structural components that appear in patient decision aids to design the proposed template for systematic reviews.

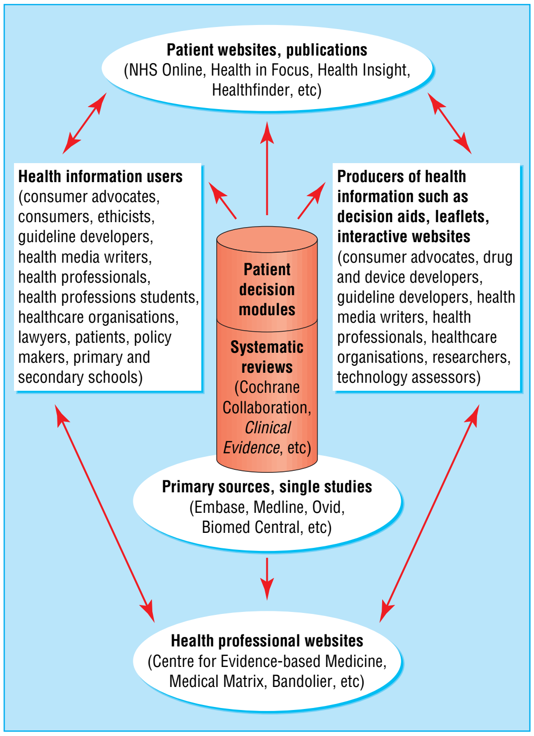
The map of opportunities

The figure shows strategic opportunities to add the proposed patient decision modules to the flow of health information. In the centre of the map is the expanding set of electronic networks providing peer reviewed, credible evidence about the effectiveness of healthcare interventions. Around it are the potential end users of medical evidence (such as consumers seeking information) and intermediary users (such as developers of patient oriented products like decision aids). The patient decision modules would be integral summaries of evidence that the authors of information summaries and systematic reviews would add (or cooperate in adding) to their works. The modules would not usually be added to single studies, since these rarely provide data on all choices for a given problem and they do not synthesise previous evidence.

What is needed to make this happen

As the figure suggests, various groups can contribute to making evidence available in a form that supports patient choice. The first are the producers of systematic reviews and other key assessments of health technology, including Cochrane Collaboration reviewers and researchers in evidence based practice centres, who could add patient decision modules to their products. Journal editors and publishers could also encourage and support this effort.

Secondly, producers of major patient websites (such as NHS Direct Online), the National Electronic Library for Health,[14] Healthfinder,[15] Health in Focus,[16] Health Insight,[17] professional websites,[18 19] and voluntary organisations and advocacy groups could request patient decision modules and commission complementary decision aids. Websites that include patient decision modules and access to decision aids may increasingly supply the “one stop” access that impatient web searchers would like to find.



Position of patient decision modules in flow of medical information

A third group are the producers of decision aids and decision support systems such as the Loeb Health Research Institute[20] and Health Dialog,[21] who could continue to develop new products based on the patient decision modules and offer access to their products via websites.

The need for integrated healthcare systems is now recognised, but these need to be supported by integrated knowledge systems and care management tools. The transmission of information to support patient choice needs to be better developed. Health education and communication have tended to be dominated by the desire to persuade patients to comply with treatment. Consumer health information materials that aim to enable people to understand, contribute to, and make decisions about their health care are still rare.[22] The implementation of evidence based patient choice requires continued efforts to address issues such as how to increase comprehension, how best to present information about harms and benefits, how to present probability data, and how to communicate uncertainty in constructive ways.

Will it work?

The purpose of our proposed patient choice modules is to bolster the movement to higher standards of informed consent and patient participation in decision making. We hope to make routine the implementation of informed consent standards such as those recommended by the General Medical Council.[23] Some barriers can be anticipated. The addition of patient decision modules would require extra work and new skills that are beyond the current capacity of many information producers. Many will lack some of the data or skills that are needed to complete the template.[24] Information producers could gain training and advice from credible centres that are independent of vested interests, in particular healthcare interventions, and that include multidisciplinary teams with all the necessary skills. These independent centres might also be commissioned to produce and update modules and materials based on their reviews.

It is important that these efforts are carried out in the public domain and that the standards and quality of patient decision modules and decision aids are monitored. There is a danger that information might be presented that seems to offer patients a choice but does not give all the alternatives or is biased towards a particular option. The development and use of credible quality indicators for decision aids would help protect potential users. Our proposed template supports such review by establishing a structured format, but individual modules and decision aids would need to be assessed in terms of their consistency with available research evidence and their accessibility and usefulness to patients. Evaluation and peer review should serve to improve standards.

The preferred style of the clinical encounter is widely assumed to have moved from paternalism to partnership.[25] Empowering consumers is increasingly seen as a cornerstone of modern health care. Our proposed template is no magic bullet. Information alone will not change the way the public, health professionals, and policy makers deliberate and interact. For example, the stability of patterns of healthcare practice tends to countermand efforts to introduce evidence based patient decision making. Incorporating decision aids into routine practice in busy medical establishments is difficult,[26] and health professionals may resist attempts to offer patients information and choice. Appointment systems for health services may need to be revised to allow time for shared decision making. However, re-framing medical discourse in terms of choices to be made and their likely consequences and in emphasising the importance of patients' goals and values is a first step.

The provision of information to patients and the facilitation of shared decision making may become measures of health system performance. Greater patient participation in decision making requires new and integrated information tools and training of health professionals so that, rather than adding complexity and burden, it enhances the health system's capacity to provide high quality health care to an informed public.

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A memorable patient
The benefits of attending the dentist

I had only recently given an undergraduate lecture on endocrine disorders when I was asked to see him. He had been referred by his dentist to the professor of prosthodontics because the provision of partial dentures was proving difficult. His mandible was long and his tongue was large, but it was the chatting about golf that made the difference. He blamed his golf handicap on his shoes as they were increasingly cramping his feet, and he commented that on recently buying a new pair, he found he had gone up a whole shoe size. The professor's sixth sense told him that something may be amiss and I was asked to see the patient. An inability to get his wedding ring on his finger, a change in facial appearance, and an increase in collar size all sounded suspicious. Further questioning revealed a history including hypertension, late onset diabetes, arthralgia, and bilateral carpel tunnel syndrome. His facial features were coarse, his hands were spade-like, and his feet were large. He did not have tunnel vision but he had enough. An endocrinological investigation quickly followed.

His acromegaly was confirmed, and he subsequently underwent successful surgery to remove a pituitary adenoma. His hypertension and diabetes have resolved and his arthralgia has improved. The soft tissue swelling of his hands has also considerably reduced, such that he is once more able to wear his wedding ring.

The diagnosis of systemic disease in a dental context is an important part of my work. Dentists have a role in the opportunistic identification of oral features of systemic disease as well as important regional and local conditions such as oral cancer. Indeed, these are some of the reasons why all dental students undergo teaching and examination in general medicine and surgery as part of their undergraduate dental degree. For some of us our interest continues (whether medical or surgical), and, in addition to our dental training, we later undertake a medical degree and postgraduate training as our career develops.

I still occasionally see him on the stairs as he ascends to the prosthodontics clinic. While his acromegaly may have been treated successfully, the provision of dentures is still proving problematic, and his golf handicap remains unchanged.

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